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ABSTRACT

The paper reviews problems and challenges in serving blind children in mental retardation facilities. Incidence figures for institutionalized blind multiply handicapped children are cited, and problems of assessing such residents are seen to include uneven development and lack of standardized evaluation measures. The impact of ward management and ward living is examined. Suggestions for normalizing the residential experience are made. (CL)

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Blind Children In Mental Retardation Facilities

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Very little is known about the population of blind children in residential mental retardation facilities. Not only has little serious research attention been paid to this population, but they are surrounded by myths, beliefs and attitudes that have resulted in lack of consistent and suitable educational and living arrangements. There are problems arising from the attitudes of people in the blindness field towards mental retardation and inadequate means of assessment of blind children by professionals trained in the mental retardation field. There are problems arising from the treatment accorded to children who are considered to be functioning at severe and profound levels of mental retardation and doubts about the educability of low functioning blind children. There has been little input from educators of blind and severely visually limited children who have an understanding of the developmental needs of the blind. There are additional problems arising from lack of family support services and the kind of information given to parents about their multihandicapped blind children. Problems also arise from lack of efficient coordination and communication between agencies serving the blind and those serving the mentally retarded. Services and consultation offered multiply handicapped children are few in number and limited in scope. These children have been given meagre and inadequate services in the community.

When a child is labeled severely or profoundly retarded several things happen. No one expects the child to be able to do anything and as a consequence, he learns to do very little.

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The label becomes a self-fulfilling prophecy. The longer the child is deprived of normal growth experiences, the more difficult he is to reach. The stimulation, isolation and withdrawn behavior observed in so many blind children in mental retardation facilities is not the result of retardedness; it is the consequence of lack of intervention during developmental periods. (Grunewald, 1973)

With the trend towards deinstitutionalization, most institutions are finding an increasing number of blind residents among their remaining populations. The fact of increasing visibility is at long last focussing attention on the needs of this population. As new programs are being developed, more is being learned about the capacities and abilities of blind children in the institutions.

Incidence of blindness in Mental Retardation Facilities.

There are large numbers of blind multihandicapped children living in state and provincial institutions for the mentally retarded in North America. Blindness is ten times more prevalent in institutions than in the community at large. Surveys indicate that about 20% of the children born blind twenty years ago now living in mental retardation facilities. (Hillman and Goddard, 1974) On wards serving severely and profoundly mentally handicapped children, the incidence of blindness is close to 11% in some institutions. On wards serving the more mildly handicapped, the percentage drops to between 3 and 5%. These percentages do not include many low vision children, who have not been identified as having severe visual handicaps.

By conservative estimate from the statistics presently available there are more than one thousand blind children in Canadian residential facilities and ten times that number in the United States.

The incidence of blindness among children diagnosed as mentally retarded is estimated at 3% in both North America and Europe. Grunewald (1973) reported that there were 955 blind persons among the 35,000 mentally retarded persons in Sweden. More than half of this population were children and young adults between the ages of 7 and 21 years. Included in this figure were 150 children with both hearing and sight defects. Warburg (1977) reported that among the 7600 mentally retarded children in Denmark, 5% were totally blind. Warburg believes that the number of mentally retarded blind children is higher than the number of blind children with normal intelligence. If children do not recognize the attendants, this is usually ascribed to low intelligence, rather than lack of sight.(Warburg, 1977) Warburg cautions that the incidence of blindness may be higher than reported, because of the many partially sighted children in instiutions who have not been identified as having severe sight problems. The fact is that there is a need for careful vision screening programs before the true numbers of visually handicapped residents of mental retardation facilities can be known.

The Problems of Assessment

Conventional procedures of assessment have little application to blind and other multihandicapped children. To add to the confusion, assessment procedures vary from one institution to the next.

Warburg estimated that 65% of the blind children in her study functioned at the severe to profound level of retardation. Her criteria were lack of speech and mobility. (Warburg, 1977) Similar percentages are reported by institutions in the United States and Canada. Rodrigues(1976) in a study of blind children in provincial institutions in Ontario, reported that less than half of the children had self-care and social skills. We found a similar proportion of children with self-care, mobility and social skills in British Columbia.

On the basis of available data it is difficult to know how many children are functioning at severe and profound levels of retardation because of lack of programs and low levels of expedtations. Statistics vary from one institution to another. However it is of interest to note that institutions which offer consistent programming for their blind residents report a smaller percentage of severe and profound retardation than do those institutions which have no, or only sporadic programs. Information from two comparable institutions show the following differences: the institution with an intensive program reports 34% of their blind residents as profoundly retarded, 27% as severely retarded, 24% as moderately retarded and 6% as mildly retarded. (Miller, 1976) .. The institution without a consistent program reports 73% as profoundly retarded, 18% as severely, 4% as moderate, 3% as mild, and 3% as borderline. Both institutions are large residential facilities serving broad cross sections of retarded populations.

Assessment of blind children is also complicated by the uneveness in development presented by so many blind children. Accurate assessment requires an understanding of the impact of blindness on early development.

The category of severe and profound retardation implies a homogeneity in areas of development that are simply not observable. Within the categories of severe and profound retardation in one large institution in British Columbia, we found that 13 of the blind residents had clear speech, good mobility skills, and good self-care skills. Nine of these residents were considered to be severely or profoundly retarded. In general, the greater the number of disabilities, such as Cerebral Palsy or Epilepsy, in addition to blindness, the greater the degree of retardation. The effects of lack of movement, medication and restraints are not generally understood. (Woods (1973) found that the blind children she studied at a hospital for the subnormal in England, walked and talked earlier than the sighted children with comparable IQs. Woods observed that severe behavior disorders such as screaming or head banging were possible manifestations of extreme frustration rather than signs of cerebral dysfunction.

The speech and language skills of the children Woods observed were very variable and ranged from no speech at all to well developed linguistic abilities. Some of the children had echolalic speech, but Woods noted that the quality of the Echolalia differed from that found among children with other types of disorders, such as Autism. Blind echolalic children often switched into meaningful speech. Woods noted many patterns of uneven development among blind retarded children.

Assessment of low functioning blind children often begins with assessment of gross motor ability. This aspect of development is most easily assessed and scored, but it is also the least valuable for the overall assessment of a child's capability. (Illingsworth, 1974)

The presence of advanced speech should always be seen as an indication of intelligent functioning and is a far better guide to a child's true capacity than gross motor ability. (Illingsworth,1974) There is also a need to look at a child's understanding of speech even when the child is non-verbal. Because of the uneveness in development found among blind children, it is unwise to express the whole of their development in one score. Allowance must be made for differences in various areas of development and changes must be made in terminology. There needs to be a shift to emphasis upon ability rather than level of retardation as presently determined.

The Impact of Ward Life

Assessment of multihandicapped blind children is further complicated by the impact of ward management and ward living. Young children placed in mental retardation facilities very often do not develop language and manipulative skills, the very abilities by which assessments of levels of retardation are made. Language development takes place in a social context. There must be verbal contact between adult and child and between child and child. These are two most important aspects of child development. It is not surprising that in the absence of these contacts, language either does not develop or it develops in deviant ways. (Oswin, 1971)

It is difficult for blind children growing up in institutions to learn the all important connections between words and their meanings. One young man, who speaks in well developed sentences, never used the appropriate words to express his basic needs, like going to the bathroom or asking for assistance. Once during a teaching session, he said, rather tensely, "Boy, will my mother be mad!" We couldn't understand the comment which was entirely out of context. His general restlessness made us inquire if he

needed to go to the bathroom. "Yes, Yes" he said with great relief. On another occasion this same fellow kept muttering what seemed to be a nonsense phrase as he walked down to the room where he worked with us. "Cox,Xox, Cox" he kept saying. The student teacher who was walking with him suddenly thought to look at his sox. Sure enough, his sox were bunching under his heels causing him discomfort. The point here is that what may seem to be a nonsense statement or inappropriate comment may be an effort at real communication expressing an urgent need.

Group relationships between the children on a ward are shaped and influenced by the way the ward is organized. Socialization is a composite of the skills, behavior and attitudes acquired by children through their contact with adults and other children. Normal social behavior is the same inside as outside of the institution. (Oswin, 1971) Children learn to differentiate among people in the course of meeting the expectations of different people. In real life mothers are different from teachers, teachers differ from grandparents and so on. On many wards, there is only one kind of expectation. Children learn that only one kind of behavior is required and responded to positively. Blind children, like the others, quickly learn the response that brings the greatest amount of attention. They learn not to differentiate among the adults when the response is always the same. The high staff turnover and shift arrangements make it impossible for the children to experience a long term relationship with any single adult. (Stephens and Robertson,)

Oswin, Stephens and Robertson and others who have made studies of children in long term care strongly advocate mixing age as well as ability groups to stimulate normal interactions between the children.

Direct-care staff are faced with the responsibility of seeing that 15 to 25 children or young adults are fed their meals, kept clean, dressed and physically comfortable. Life on the wards revolves around routines. Nursing and other direct-care staff, even when they recognize the need for more personalized attention, find it difficult to carry out their tasks in a personal way. With more severely handicapped children, there is little talking or interacting with the children. The timetable allows only so many minutes for feeding, dressing, bathing etc. This depersonalization is reflected in staff relations as well as staff/child relations. On one ward, there were colorful hand-printed signs giving instructions to ward staff on the handling of the children. Above the crib of one small blind child, who is mobile, and gives evidence of having receptive language, and is sociable, there is the following sign.

> Hello. My name is Brenda. I sit in a tenda. You should be able to find me near my bed. I have porridge. Take it away if you find me playing with my spoon.
> I chase the porridge with apple juice.(hard glass please) Could you take time to watch me have my juice? I can pick it up and return it on my own. You might have to remind me to do this pronto-but don't pick up the glass for me.

Hours between routine activities are spent sitting in a day room with a television set placed high near the ceiling. We could observe very little contwct between adult and child or between child and child. The blind child sat and soon fell asleep with her head on her knees. The hours a child sleeps during the day may cause him to lie awake at night. For this the child is given medication, which makes it difficult for them to stay awake during the day.

When these same children are handled in small groups and provided with personal attention and toys to manipulate, they seem to be almost immediately transformed.

We observed children being fed at mealtimes. Those that were able to feed themselves simply shoved their food into their mouths with little indication of enjoyment. Very little social behavior was noted. The joylessness of the children was apparent by the speed with which they ate. There was no sense of shared experience that is characteristic of children in families at mealtimes. These children seemed to know that eating quickly and quietly is the preferred behavior because it causes less fuss.

Since contact with adults only happens around routines; this is the obvious place to personalize contact and give the children a sense of being important to an adult. The organization of many wards teaches direct care staff, against their better judgement, to ignore childrens' appeals for attention. Many children learn to give up trying for attention and wrap themselves in the armor of withdrawal and a "learned helplessness". A classic illustration of "learned helplessness is where animals, placed in a situation where they are unable to excape punishment, soon extinguish all previously learned adaptive and avoidance behavior. Any child forced to exist in a social environment that devalues the child and expects only low levels of competence, will have problems developing adequate social skills. Educational efforts must be combined with a concurrent effort to change the social environment into one which is responsive and capable of meeting emotional as well as physical needs.

The problems that blind children face on these wards makes it nearly impossible for them to acquire the social skills that are necessary to survive outside of the institution. A complete overhaul of ward management is required to place children in small groups, retrain direct care staff, change staff priorities and provide

long term programs on wards as well as in classrooms. Deinstitutionalizatio may result in the building of smaller units, but unless there is a change in the attitudes and expectations of administrations, a shift in emphasis in ward care, and personalization of treatment, the results will be the same.

For a variety of reasons many blind children in provincial and state institutions have lost contact with their families. Little attention has been given to the factors that make it difficult for parents to maintain contact with their children. And when they do not see any progress, parents may experience a nagging guilt about the decision to place their child in long term care. Decisions to place a child in a residential institution are usually made after long struggles to maintain the child in the home. Lack of community facilities, behavior problems, family breakdown, and illness of parents are among the leading reasons for placement in long term care. In our study of a British Columbia institution, we found that fewer than 14% of the blind residents saw their families once per month or more. 50% had no contact with their families. There must be an effort to involve the families of children in long term as well as short term planning for their children. There is no child so handicapped that he does not suffer from loss of contact with his family.

For children without consistent contact with their parents, it is all the more necessary that their emotional needs be met by sustained and continuous contact with caring adults. Oswin, (1971) in her study of physically handicapped children in long stay hospitals found that children suffer emotional distress because of the lack of understanding about the "mothering" needs of children in institutions. Oswin defines mothering as personalized attention, warm one to one relationships, which help children to define

themselves and understand the world around them. Oswin writes:

> Most of us in the NHS (National Health Service) today can talk very grandly about social policies, assessment, integration, and 10 year plans, but how much do we really understand about mothering of children in institutions? It is far more fashionable today to talk about multidisciplinary assessment teams than to talk about mothering, but it would seem that there is a need for this very simple word-mothering-to be brought back into fashion, especially amongst those of us who work with handicapped children in institutions. The child's whole quality of life in long stay hospital will depend on how much is understood about his mothering needs. (p.351)

Educational and behavioral technology is becoming quite sophisticated but unless it can be applied and combined with knowledge of human development, our technology can develop little more than splinter skills and minimal survival skills. Personalization of care, time and attention from consistent adults, well-trained therapists and teachers can change the futures for blind children in our mental retardation facilities.

The Normalization of Experience

There is the need for developmental programs for blind children so that they do not experience "just sitting around idly as passive consumers in meaningless situations" (Grunewald,15) Special wards need to be developed by the same team of professionals who make the diagnosis and who have the responsibility for providing treatment, management and education.

Blind children can respond to an environment which is planned to bring the children into contact with it. These children need to understand what is happening around them. Planning needs to be done for children in smaller groups, so that it will be easier to find out about each individual, what he can do, and how to help him relate to reality and become activated.

There must be opportunities created for children to use the abilities they have and practice the skills they are learning. There need to be toys and other objects that can be explored, manipulated

and enjoyed.

There is an important interplay between all areas of development. Children who live in residential care need to learn to play, to talk, to know fun and joy. Direct-care staff need to spend time in classrooms and teachers need to spend time on the wards. Where there is close cooperation between professionals and administrators, nurses and teachers, teaching and learning becomes a more continuous process for the children. Education programs are being developed within institutions for blind multihandicapped children. They are becoming goal oriented and are designed to enable children to move back into the community. But unless the skills they teach can be activelyemployed and made meaningful in day to day living on the ward, they will become splinter skills. Children need opportunities to put their learning to use, to feel good about their accomplishments, and to share their pride with people who care about them.

Normalizing life for blind children in mental retardation facilities is not the awesome task it appears. It is a matter of adults working with adults to create environments that are conducive to growth and learning.

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